



Family Caregiver

Sharing Information & Giving Support to Hawai'i's Family Caregivers

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Behavior Mod Gone Awry

by Geri Ah Sam

We all have fond memories of our care giving experiences. This one in particular always brings a smile to my face.

My father, Manuel P. Martins, became interested in growing orchids upon his retirement as a machinist for the Puunene Mill of Hawaiian Commercial and Sugar Company. He would even make the cement pots out of molds that he built. He was a member of the Maui Orchid Society, which was a source of pride for him.

IN SPITE OF BEING

WHEELCHAIR BOUND, HE

FOUND A JAR OF CANDY ON A

DESK IN ONE OF THE OFFICES.

As the years went by, he spent less time with his plants and moved toward a "cloud" of some kind, not remembering where he left tools or where he had set something down.

The hardest thing I ever had to do was take away his car keys. On occasion, he would drive off, at which time I would leave work and look for him. He would always say that he was going to Holy Family Church for

mass, no matter what day or time it was. Holy Family was the Catholic parish in the plantation village where I lived as a young child.



One afternoon dad fell in the yard. An ambulance was called and he was admitted to Maui Memorial Hospital. We learned that he had Sundowner's Syndrome. After two surgeries to remove blood clots from his brain, he was better. But he also became combative and would strike out at the staff. It was so hard to imagine this quiet, articulate, smart man turning into someone we didn't know.

We decided to admit him to Kula Hospital. His room was on the first floor where administration offices were located. In spite of being wheelchair bound, he found a jar of candy on a desk in one of the offices. Staff tried everything to keep him out of the offices, and I even brought his own candy every Sunday

and showed him where it was in his nightstand.

Finally, I decided that we would try to modify his behavior in some way. We made an octagonal shaped red and white traffic sign and hung it in the corridor leading to the office. A black line was painted on the floor directly under the sign, which instructed my father to come to a standstill and look up at the sign that said "STOP MANUEL." I agreed to be there the first day to introduce him to the idea.

First, I showed him the candy in his drawer. I then asked him to take me to where he gets the "other candy." He wheeled himself down the hallway to the corridor leading to the offices. At the black strip, I asked him to stop and read the sign. He did in fact read the sign out loud to me. But when I asked him if he knew why the sign was there, he replied "I don't really know why that sign is there, but I can tell you for a fact that someone named Manuel is in really hot water."



Upcoming & etc...

STATEWIDE

Hawai'i's Caregiver Coalition

Hawai'i is in its infant stages of building a statewide Caregiver Coalition. Founding members received training by the AARP Foundation on July 28 and 29, 2004. As a result of the training, we defined our mission statement: "As care giving touches everyone, the mission of the Hawai'i Caregiver Coalition is to improve the quality of life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education and outreach." If you would like more information about Hawai'i's Caregiver Coalition, please contact the EOA at 586-7319.

The Power of Choice: An Online Chat Forum for Hawai'i Caregivers

November 18, 2004

3:30 - 4:30 pm

This exciting, new online chat offers the opportunity to join a team of local experts for a series of up-to-date chat sessions to anyone interested in learning about long-term care issues and having the power to make decisions for yourself, your family, and loved ones. Log on to www.RealChoices.org/chat.

HONOLULU

American Red Cross Family Caregiver Training in Honolulu

The Elderly Affairs Division and the Department of Human Resources are jointly facilitating nine sessions of the American Red Cross Family Caregiver Training Program at no cost to participants. Topics include: home safety, general care giving skills, assisting with personal care, positioning and helping your loved one move, healthy eating, caring for the caregiver, legal and financial issues, caring for a loved one with Alzheimer's or dementia, and caring for a loved one with HIV/AIDS. For more information, contact the Elderly Affairs Division at 523-4545.

Family Caregiving Training – Fall Sessions

Family Caregiving Training sessions will begin on September 11 and run for 6 Saturdays from 9:00am - Noon at Central Union Church. Topics include: what is normal aging, community resources, safety & mobility, personal care and nursing skills, nutrition & medications, elder law and basic estate planning, cost of long-term care and how to pay for it, and end of life care and bereavement. Self-care for family caregivers will be part of all sessions, and there will be time for discussion, questions, and sharing. FREE for family caregivers. Sponsored by the Franciscan Adult Day Center and coordinated by Eldercare Hawai'i. For more information, call 988-6300.

Economics of Aging: Financing the Golden Years

October 7-8, 2004

Radisson Waikiki Prince Kuhio Hotel
Hawai'i Pacific Gerontological Society 13th Biennial Conference. Visit www.hpgs.org to download a registration form.

ISLAND OF HAWAII

Kona's Carousel of Care: A Caregiver's Conference

October 30, 2004

King Kamehameha's Kona Beach Hotel
For more information, call the Hawai'i County Office on Aging at 327-3597.

Where Do I Start?

The best place to start in getting information on caregiver services in your community is your county office on aging. They can be reached at the following numbers:

Honolulu Elderly Affairs Division
523-4545

Kaua'i Agency on Elderly Affairs
241-4470

Maui County Office on Aging
270-7755

Hawai'i County Office on Aging
961-8600 (Hilo)
327-3597 (Kona)

MAUI

Maui's 3rd Annual Caregiver's Conference

November 6, 2004

Maui Beach Hotel

For more information, call the Maui County Office on Aging at 270-7755.

Maui County Employees as Caregivers Seminar

November 19, 2004

For more information, call the Maui County Office on Aging at 270-7755



E LOA KE OLA



MAY LIFE
BE LONG

The Executive Office on Aging is the state agency whose mission is to promote dignity and independence of older adults, and to help prepare for the rapid expansion of Hawai'i's aging population.

Phone: 808-586-0100
www2.state.hi.us/eoa

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H O N O L U L U

Caring for Family, Caring for Yourself: A Caregivers Conference, held on July 10th at the Sheraton Waikiki, was considered a huge success by



the 650 caregivers and community members who attended the event. Family caregivers learned about available resources and information to help ease their care giving tasks. Attendees also took the opportunity to network and share best practices.

Keynote speaker Lee White, the National Director of State Operations for AARP, mesmerized the capacity crowd when he talked about his own caregiver's story, "Keeping Things Together Without Falling Apart."

The conference connected the caregivers with 25 presenters experienced in the aging and care-giving field who understand caregiver's needs. Topics were designed to help family caregivers develop effective problem-solving skills in their care giving roles, as well as help to further their basic knowledge about care giving and the ability to cope when dealing with stressful situations.

The 21 concurrent sessions ranged from making the home caregiver-friendly, monitoring prescription drugs, legal issues, hospice care,

making the right choices, to handling difficult behaviors, dealing with stress and avoiding burnout through music therapy. Conference goers also learned about money management resources and the latest about deductible costs and other tax deductions and credits associated with care giving. All the sessions provided essential knowledge and hands-on skills geared to assist family caregivers.

The conference also connected attendees to an array of information-



al community resources. Forty-nine exhibitors featured a variety of informational resources that included various care options, resources and services. Participants had the option of indulging in an assortment of self-care activities including aromatherapy, lomi-lomi and shiatsu massages; bio-magnetic and healing touch techniques, plus best practices of foot care.

The event sponsors AARP, Alu

Like, HMSA, Hospice Hawai'i, and the Elderly Affairs Division agreed that supporting caregivers through informational and training conferences not only have a positive impact on caregivers, but their family members as well. The health and well being of caregivers is more important than ever because of the large number of family caregivers taking care of older persons. It enables caregivers to be effective caregivers and allows them to continue providing care. It's a sound investment that delays nursing home placements and reduces costlier long-term facility care.

Plans are already underway for next year's conference tentatively scheduled for August 27, 2005.

M A U I

The Maui County Office on Aging (MCOA) has contracted with CareTrust Publications to produce "Caregivers - Let's Take Care of You!" newsletter. The newsletter is mailed free of charge to family caregivers. The genesis of the project was a short staff and aging network discussion on "Tips for Caregivers Maui Style" that took place over a year ago. If you would like to add your name and address to the mailing list, contact MCOA at 270-7774.

Maui's Grandparent Coalition recently chose a name for itself that embraces the spirit and direction of its efforts. The coalition's new name is Hi'i Na Kupuna - To Embrace (or support) the Kupuna. See Tutu's Corner for a photograph of its August 18, 2004 meeting.

H A W A I ' I

Over 300 people attended the Caring for Family, Caring for Yourself: A Caregiver's Conference on August 5, 2004, at the Hilo Hawaiian Hotel. It was a very successful event.

Comments from caregivers left no doubt that they had gained refreshment of soul and information they could apply. "It was awesome!" "It provided us with information that is so BADLY needed...it constantly reinforced the importance of who we are and what we are doing...we

(Continued on page 4.)

What is Hawai'i Rx Plus?

Hawai'i Rx Plus is a prescription drug discount program intended to help those who do not have all their drugs paid for by insurance. This program will allow you to purchase your drugs at the same discount that the Department of Human Services (DHS) pays for Medicaid recipients.



Regular insurance is usually better than a drug discount program such as the Hawai'i Rx Plus program, so please keep any drug insurance that you may already have and apply for the Hawai'i Rx Plus discount card, too.

Eligibility

You are eligible to enroll in this program if:

- You are a Hawai'i resident. You do not have to be a resident for a certain amount of time (ex. 6 months, 1 year, etc.)
- You do not have all of your drugs paid for by insurance
- Your household's income (before deductions—not take home pay) within the last 12 months did not exceed 350% of the Federal Poverty Level (FPL) for the State of

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County Corner

(Continued from page 3.)

learned to protect ourselves so that we can take care of others with wisdom, security, and love." "God bless all caregivers...there is love in the process of caring." "I absorbed so



much information...I had no idea what was available and I'm looking forward to next year's presentations." The caregivers' efforts and dedication were validated and they found comfort in knowing they are NOT alone in their caregiving journey.

Each of the presenters connected with their audience as they shared pertinent and valuable information. James Pietsch, Esq. and Lenora Lee, authors of *Deciding "What If?" A Legal Handbook for Hawai'i Caregivers, Families, and Older Persons*, presented the morning keynote. With Mr. Pietsch's sense of humor and ability to transform complex issues into simple concepts, caregivers

were made privy to the practical and helpful information on legal issues outlined in the handbook.

The afternoon keynote address by Brian Iwata, CPA, entitled "Important Tax Information for Caregivers," focused on whether or not deductibles and credits are available to caregivers. Twelve other sessions were available that addressed the concerns of the "soon-to-be caregiver" to persons providing higher levels of care. With each presentation uniquely targeting the multi-dimensional caregiver, sessions included information on community resources, long-term care placement options, mental health care, caregiver transfer techniques, money management, and a caregiver "talk story" session.



Twenty local service providers and agencies participated in the conference's Resource Fair. Vendor tables displayed information and products with helpful tips and tools to assist the caregiver at home.

HCOA would like to thank its conference partners (AARP, HMSA, and Alu Like), and extend a special *mahalo* to the Elderly Affairs Division of Oahu and Karen Miyake of the Executive Office on Aging, for sharing the "Deciding 'What If?'" handbook.

It worked for me

with Karen Koles



Q: Can you give us some hints about clothing for my mom?

A: Look for 100% cotton when shopping for sheets, shirts, underwear, everything that your mom will use. Reason? Cotton “breathes” while polyester & cotton/polyester blends tend to hold in body heat.



The professionals at the Rehab gave us really great advice when they suggested that we do not allow our loved one to remain in pajamas or hospital gowns 24-hours a day. We dressed dad in large t-shirts that had been slit up the back with bias tape ties sewn at the neck opening. My sister sewed large colorful bermuda shorts with very loose elastic threaded through the waistband and snaps instead of zippers. It was very easy to dress dad even though he was an invalid.

For a woman, brightly colored muumuus would be ideal. It'll be easier to dress your mom if the muumuu is sleeveless or has large sleeves and if the neckline is not snug. Be sure that when you put your mom or dad into the wheelchair, that the clothing doesn't hitch up or bind, which could be rather uncomfortable.

Another caregiver swears by using Velcro as fasteners. Her dad is a stroke survivor who is intent on dressing himself but is really challenged when it comes to fastening buttons. She solved this problem

(and preserved his dignity) by removing the buttons then re-stitching them to the buttonhole side of the shirt. She then ironed on Velcro strips where the buttons had originally been and to the underside of the buttonholes. With a little bit of ingenuity, even zippers could be replaced with Velcro!

Q: What hints can you give about doing my mom's laundry?

A: We ran dad's laundry through the “prewash” cycle, using a small amount of liquid laundry soap and the hottest water possible. This rinsed out any urine, spilled food, etc. Then we reset the washer on the heavy-duty cycle (for better agitation), used the normal amount of laundry soap (less the amount used in the prewash cycle), and again, used the hottest water possible. The rinse cycle used cold water. When the machine stopped, we



reset the washer for another wash and rinse cycle, but used cold water.

This put the laundry through three rinse cycles. This way, we were pretty sure that all the soap had been rinsed out, and the laundry dried soft and fluffy. You will notice that we did not use any liquid fabric softener in the washing machine or fabric softening sheets in the dryer. Fabric softeners tend to build up with repeated use; towels become much less absorbent.

If you have a clothes dryer, use it at the hottest setting. This really sanitizes the clothes.

Q: What are Chux?

A: Chux are absorbent, plastic-lined,

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disposable protectors that make caregiving a lot easier. They can be used under a person lying in bed to soak up anything that leaks from a diaper, is great to absorb moisture during a bed bath or under your loved one when sitting in a wheelchair.

The “negative” side of chux is the heat build up. Try this yourself, lie down on a chux. You'll soon feel the heat. Now, if you have a backache, lying on a chux brings warm relief. But if you're bed bound or have difficulty turning in bed, you can imagine in today's weather how uncomfortable this would quickly become.

Disclaimer: The suggestions in It Worked for Me were found to be helpful by contributing caregivers and are not to be interpreted as fact or intended to guarantee similar results.

READERS:

WHAT WOULD YOU LIKE TO READ
ABOUT IN FUTURE COLUMNS OF
“IT WORKED FOR ME”? WE WANT
TO HEAR FROM YOU!

CALL US AT
586-0100



Tutu's Corner

Na Tutu: Grandparents Raising Grandchildren

by Jackie Chong, Chairperson, Na Tutu

In 1999, the Windward Oahu Family and Community Education Council participated in a satellite videoconference sponsored by the University Cooperative Extension Services entitled, "Grandparents Raising Grandchildren." The videoconference detailed the difficulties of receiving necessary and proper education and medical services for minor children who were

PRIOR TO THIS LAW, THE CHILDREN HAD TO BE ENROLLED IN THE SCHOOLS OF THEIR PARENTS' LAST KNOWN ADDRESS, AND OFTEN TIMES, THAT COULD HAVE BEEN ACROSS OF THE ISLAND.

being cared for by grandparents or relative caregivers. Growing interest and concern following this videoconference blossomed into Na Tutu, and a four-year struggle for legislation that would allow grandparents and relatives to care for these children in the traditional "hanai" system.

There were three of us who were particularly interested in this project: Julia Duarte, who had raised a nephew and knew of the difficulties of receiving medical attention when needed; Carole Mulford, a step-mother of a growing young man; and I, who

has cared for nephews, nieces, and grandchildren throughout my lifetime.

We met with the Queen Liliuokalani Children's Center (QLCC) and learned of the many programs that were available to orphaned children under the Queen's Trust. We found that we were both working for the same target group, the children. QLCC offered support and we quickly joined forces with additional agencies and associations.

We formed two groups: a support group and a coalition group. The support group offered educational

the parents are unable or unavailable for signatures. Prior to this law, the children had to be enrolled in the schools of their parents' last known address, and often times, that could have been across of the island. District exceptions were unobtainable because parents were unavailable for signature.

Our next endeavor was at the 2004 Legislature advocating for a medical consent bill that would authorize an adult over the age of eighteen to consent for medical services for minor children in their care after



Hi'i Na Kupuna, Maui's Grandparent Coalition, met on August 18, 2004.

programs and recreational activities to grandparents and relatives facilitated by licensed social workers of QLCC. The coalition group, headed by determined grassroots grandparents, sought legislation for "consent" laws. "Consent" laws would allow us to care for our minor relatives, enroll them in school, and receive necessary medical benefits.

After four years of dedication and persistence, the Na Tutu "Caregiver Consent" bill was signed into law. Act 99 (2003) allows grandparents and relative caregivers who are caring for children to enroll them in the schools in the district in which they live, if an affidavit is completed stating that the children have been in their care for at least six months and

submitting an authorization affidavit. Medical services would include immunizations, dental, vision, physical, and mental health services. In Hawai'i, there is already a provision in place which allows for immunizations without parental consent, and in emergency situations, physicians, after conferring, may provide medical care. However, dental, vision, physical, and mental health services are unavailable to children unless parental consent is obtained. While this proposal failed to pass the Legislature in 2004, we will be advocating for this in 2005.

If you would like to assist in our advocacy efforts, or would like more information about Na Tutu, please contact Jackie Chong at 239-8908.

Caregiver Support on the Windward Side

The inspiration to begin a monthly support group on the Windward side came from Ree Hiatt, a resident and caregiver, who traveled into Honolulu to attend caregiver support meetings. Travel to meetings, especially by bus, was not only time consuming but expensive. Substitute caregivers also had to be hired while

Featured Caregiver Support Group

CASTLE MEDICAL CENTER CAREGIVER'S SUPPORT GROUP

CONTACT: SUE PIGNATARO
PHONE: 247-2828

Ree was away. Often feeling isolated and alone, Ree understood the importance of receiving support from other caregivers. After Ree's Mom died and her care giving responsibilities ended, she continued to reach out to the community through health related activities at her church and often spoke with new caregivers to provide support and encouragement. She participated in Parish Nurse/Health Ministry meetings held at Castle Medical Center and suggested a support group for Windward community caregivers. The Castle Caregiver Support Group began in April of 1996 and Ree was a regular participant. She would often explain, "I am here to prove that there is life after care giving."

The Windward Caregiver Support Group has focused on education and peer support. A Registered Nurse with many years of experience as a Home Health Nurse facilitates the session. Guest speakers are invited each month to address a topic related to caregiver concerns. Topics may cover resources available in the community or specific care giving skills such as skin care and bed sore prevention. In September, a representative from the Alzheimer's Association will discuss how to manage difficult



**ATTENDEES UNDERSTAND
THAT ONLY OTHER
CAREGIVERS CAN TRULY
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behaviors related to people with dementia. A speech pathologist will address swallowing issues in October. Some sessions focus on caregivers' feelings, such as anger, frustration and loss, as well as coping strategies, relaxation techniques and the importance of getting adequate help. There is always time for sharing and expressing concerns and feelings. Tears of pain and sadness are shed while relief is found through the laughter and a genuine caring of one another.

Caregivers who attend the group

may be a spouse, adult child, other family member or friend of the care-receiver. Some members attend every month while others are intermittent depending on the topic and other commitments. New members are always welcome. To help keep the group informed, a mailing is sent prior to each meeting which details the focus of the meeting and includes information about some aspect of care giving for ongoing education. Phone calls to the nurse facilitator are welcome for questions and concerns that arise between meetings. Some members have chosen to meet socially for a dinner gathering once a month. Attendees understand that only other caregivers can truly understand the challenges they face each day. Through this heartfelt compassion and care of each other, renewal occurs and strength is found to face another day.

The Castle Medical Center Caregivers' Support Group meets the last Wednesday of every month at 10:00 AM - 12 noon in the Pikake Room. Call Sue Pignataro at 247-2828 for more information.

What is Hawai'i Rx Plus?

(Continued from page 4.)

Hawai'i, according to family size.

Even if you have insurance we encourage residents to still apply as not ALL drugs are covered by insurance policies.

Are there any asset limitations?

No. Assets are not considered in determining eligibility to participate in Hawai'i Rx Plus.

How can I sign up?

Call 211 to request an application form. The phone call is free from all islands. Or visit www.hawaiiirxplus.com to download an application. Application forms are also available from any DHS Med-QUEST Division Office, participating pharmacies, AARP Hawai'i, and community health centers.

Only one application for all family members living in one household at the same address is needed.

When will my coverage under the Hawai'i RX Plus Program begin?

After an application is approved, the applicant and their family members will receive a Hawai'i Rx Plus discount card. Discounts begin the day you receive the card.

How much is the discount?

Depending on the drug, consumers can expect to save an estimated 10-15% off of the average wholesale price of drugs during the first year. Beginning in 2005 consumers will be able to enjoy an even bigger discount when the State begins receiving manufacturer rebates from pharmaceutical companies. The more residents that enroll into this program, the bigger the discount will be. Hawai'i Rx Plus will not give you a discount on your co-payments.

What drugs are covered by this discount?

All drugs are covered by this discount.

Can I still participate if I am enrolled in other discount programs?

Yes. Enrolling into the Hawai'i Rx Plus program will not dis-enroll or disqualify you from any other prescription

drug discount program that you may qualify for. We strongly encourage qualified residents to enroll in all of the different programs that are available, including the Medicare Prescription Drug program, Medicaid/QUEST, and Hawai'i Prescription Care. However, you may not combine all of your prescription drug discount cards for additional discounts.

Will I be able to get a discount on the drugs I get through mail-order?

No. The Hawai'i Rx Plus card is only good at participating Hawai'i pharmacies.

Who do I contact for more information?

For more information about this program, call 211. The phone call is free, confidential, and 24/7 from all islands. You may also e-mail webmaster@hawaiiirxplus.com.

If you have questions about the status of your application, O'ahu residents may call (808) 692-7999 and Neighbor Island residents may call toll-free 1-866-878-9769.

E LOA KE OLA



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